

Union Calendar No. 163

108TH CONGRESS
1ST SESSION

H. R. 3034

[Report No. 108-276]

To amend the Public Health Service Act to reauthorize the National Bone Marrow Donor Registry, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 5, 2003

Mr. YOUNG of Florida (for himself, Mr. BILIRAKIS, and Mr. TOWNS) introduced the following bill; which was referred to the Committee on Energy and Commerce

SEPTEMBER 17, 2003

Additional sponsors: Mr. TOM DAVIS of Virginia, Mrs. CAPPS, Mrs. CHRISTENSEN, and Mr. MEEKS of New York

SEPTEMBER 17, 2003

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italic]

[For text of introduced bill, see copy of bill as introduced on September 5, 2003]

A BILL

To amend the Public Health Service Act to reauthorize the National Bone Marrow Donor Registry, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
 2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 *This Act may be cited as the “National Bone Marrow*
 5 *Donor Registry Reauthorization Act”.*

6 **SEC. 2. NATIONAL BONE MARROW DONOR REGISTRY.**

7 *(a) NATIONAL REGISTRY.—Section 379 of the Public*
 8 *Health Service Act (42 U.S.C. 274k) is amended—*

9 *(1) in subsection (a)—*

10 *(A) in paragraph (1), by striking “except*
 11 *that” and all that follows and inserting “except*
 12 *that—*

13 *“(A) such limitations shall not apply to the*
 14 *Chair of the board (or the Chair-elect) or to the*
 15 *member of the board who most recently served as*
 16 *the Chair; and*

17 *“(B) 1 additional consecutive 2-year term*
 18 *may be served by any member of the board who*
 19 *has no employment, governance, or financial af-*
 20 *filiation with any donor center, recruitment*
 21 *group, transplant center, or cord blood bank.”;*
 22 *and*

23 *(B) in paragraph (4)—*

24 *(i) by striking “the Naval Medical Re-*
 25 *search and Development Command” and*

1 *inserting “the Department of Defense Mar-*
2 *row Donor Recruitment and Research Pro-*
3 *gram operated by the Department of the*
4 *Navy”; and*

5 *(ii) by striking “Organ” after “Divi-*
6 *sion of”;*

7 *(2) in subsection (b)—*

8 *(A) in paragraph (4), by inserting “at*
9 *least” before “annually”;*

10 *(B) in paragraph (7), by striking “and*
11 *comparisons of transplant centers regarding*
12 *search and other costs that prior to transplan-*
13 *tation are charged to patients by transplant cen-*
14 *ters; and”;*

15 *(C) in paragraph (8), by inserting “and*
16 *outreach” after “and demonstration”;*

17 *(D) at the end of paragraph (8), by striking*
18 *the period and inserting a semicolon;*

19 *(E) by redesignating paragraphs (3)*
20 *through (8) as paragraphs (4) through (9);*

21 *(F) by inserting after paragraph (2), the*
22 *following:*

23 *“(3) maintain and expand medical emergency*
24 *contingency response capabilities in concert with Fed-*
25 *eral programs for response to threats of use of ter-*

1 *rorist or military weapons that can damage marrow,*
2 *such as ionizing radiation or chemical agents con-*
3 *taining mustard, so that the capability of supporting*
4 *patients with marrow damage from disease can be*
5 *used to support casualties with marrow damage;”;*
6 *and*

7 *(G) by adding at the end the following:*

8 *“(10) conduct and support research to improve*
9 *the availability, efficiency, safety, and cost of trans-*
10 *plants from unrelated donors and the effectiveness of*
11 *Registry operations;*

12 *“(11) increase the number of umbilical cord*
13 *blood units listed in the Registry and assist cord*
14 *blood banks in the Registry program in accordance*
15 *with subsection (c); and*

16 *“(12) establish bylaws and procedures—*

17 *“(A) to prohibit any member of the board of*
18 *directors of the Registry who has an employ-*
19 *ment, governance, or financial affiliation with a*
20 *donor center, recruitment group, transplant cen-*
21 *ter, or cord blood bank from participating in*
22 *any decision that materially affects the center,*
23 *recruitment group, transplant center, or cord*
24 *blood bank; and*

1 “(B) to limit the number of members of the
2 board with any such affiliation.”;

3 (3) in subsection (c)—

4 (A) in clause (ii) of paragraph (2)(A), by
5 striking “, including providing updates”; and

6 (B) in paragraph (3), by striking “the
7 availability, as a potential treatment option, of
8 receiving a transplant of bone marrow from an
9 unrelated donor” and inserting “transplants
10 from unrelated donors as a treatment option and
11 resources for identifying and evaluating other
12 therapeutic alternatives”;

13 (4) in subsection (d)—

14 (A) in paragraph (2)(C), by inserting “and
15 assist with information regarding third party
16 payor matters” after “ongoing search for a
17 donor”;

18 (B) in paragraph (2)(F)—

19 (i) by redesignating clause (v) as
20 clause (vi); and

21 (ii) by inserting after clause (iv) the
22 following:

23 “(v) Information concerning issues
24 that patients may face after a transplant

1 *regarding continuity of care and quality of*
 2 *life.”; and*

3 *(C) in paragraph (3)(B), by striking “Of-*
 4 *fice may” and inserting “Office shall”;*

5 *(5) in subsection (g), by striking “the bone mar-*
 6 *row donor program of the Department of the Navy”*
 7 *and inserting “the Department of Defense Marrow*
 8 *Donor Recruitment and Research Program operated*
 9 *by the Department of the Navy”;*

10 *(6) in subsection (h)—*

11 *(A) by striking “APPLICATION.—” and in-*
 12 *serting “CONTRACTS.—”;*

13 *(B) by striking “To be eligible” and insert-*
 14 *ing the following:*

15 *“(1) APPLICATION.—To be eligible”; and*

16 *(C) by adding at the end the following:*

17 *“(2) CONSIDERATIONS.—In awarding contracts*
 18 *under this section, the Secretary shall give substantial*
 19 *weight to the continued safety of donors and patients*
 20 *and other factors deemed appropriate by the Sec-*
 21 *retary.”;*

22 *(7) in subsection (i), by striking “include” and*
 23 *inserting “be”; and*

24 *(8) by striking subsection (l).*

1 (b) *BONE MARROW SCIENTIFIC REGISTRY*.—Section
 2 379A of the Public Health Service Act (42 U.S.C. 274l) is
 3 amended—

4 (1) in subsection (a), by adding at the end the
 5 following: “The scientific registry shall participate in
 6 medical research that has the potential to improve
 7 transplant outcomes.”;

8 (2) in subsection (c), by striking “Each such re-
 9 port shall in addition include the data required in
 10 section 379(l) (relating to pretransplant costs).”; and

11 (3) by adding after subsection (c) the following:
 12 “(d) *PUBLICLY AVAILABLE DATA*.—The scientific reg-
 13 istry shall make relevant scientific information not con-
 14 taining individually identifiable information available to
 15 the public in the form of summaries and data sets to encour-
 16 age medical research and to provide information to trans-
 17 plant programs, physicians, and patients.”.

18 (c) *BONE MARROW AND MARROW DEFINED*.—Part I
 19 of title III of the Public Health Service Act (42 U.S.C. 274k
 20 et seq.) is amended—

21 (1) by redesignating section 379B as section
 22 379C; and

23 (2) by inserting after section 379A the following:

1 **“SEC. 379B. BONE MARROW AND MARROW DEFINED.**

2 *“For purposes of this part, the terms ‘bone marrow’*
 3 *and ‘marrow’ include bone marrow and any other source*
 4 *of hematopoietic progenitor cells the acquisition or use of*
 5 *which is not inconsistent with Federal law.”.*

6 (d) *AUTHORIZATION OF APPROPRIATIONS.—Section*
 7 *379C of the Public Health Service Act, as redesignated by*
 8 *subsection (c), is amended to read as follows:*

9 **“SEC. 379C. AUTHORIZATION OF APPROPRIATIONS.**

10 *“(a) IN GENERAL.—For the purpose of carrying out*
 11 *this part, there are authorized to be appropriated*
 12 *\$32,000,000 for fiscal year 2004, and such sums as may*
 13 *be necessary for each of the fiscal years 2005 through 2008.*

14 *“(b) EMERGENCY CONTINGENCY RESPONSE CAPABILI-*
 15 *TIES.—In addition to the amounts authorized to be appro-*
 16 *priated under subsection (a), there are authorized to be ap-*
 17 *propriated such sums as may be necessary for the mainte-*
 18 *nance and expansion of emergency contingency response ca-*
 19 *pabilities under section 379(b)(3).”.*

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